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The needs of professionals in the palliative care of children and adolescents

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Abstract The main objectives of this qualitative study were to describe the perceptions and needs of pediatric health care professionals (HCPs) taking care of children with palliative care needs and to develop a concept for the first Center of Competence for Pediatric Palliative Care (PPC) in Switzerland. Within two parts of the study, 76 HCPs were interviewed. The main interview topics were: (1) definition of and attitude toward PPC; (2) current provision of PPC; (3) the support needs of HCPs in the provision of PPC; and (4) the role of specialized PPC teams. HCPs expressed openness to PPC and reported distinctive needs for support in the care of these patients. The main tasks of specialized PPC teams in Switzerland would encompass the coaching of attending teams, coordination of care, symptom control, and direct support of

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Keywords Palliative care · Children · Healthcare professionals · Needs · Specialized pediatric palliative care

Introduction

Palliative care including pediatric palliative care (PPC) with its particular focus on quality of life (QOL) may lead to better patient and caregiver outcomes [2, 26]. Thus, according to the recommendations of the Institute of Medicine [11] and the Association for Children's Palliative Care (ACT) [1], palliative care should be initiated early in the course of a life-limiting disease. In adults suffering from advanced cancer, randomized controlled trials have demonstrated that palliative care provided concurrently with standard oncology care not only improved QOL, but also survival [23, 25]. Therefore, the American Society of Clinical Oncology released a provisional clinical opinion that strongly suggests integrating palliative care into standard oncology care early in the course of illness for patients with metastatic cancer and/or high symptom burden [23]. In practice, however, palliative care and referrals to specialized PPC services occur comparatively late in the course of life-limiting diseases in children [8, 26]. Individual structural and cultural barriers to PPC have been described; some of them may point to uncovered needs of professionals such as specialized PPC support in the care of these patients [5, 14, 21, 26].

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In Switzerland, there are only few data about the provision of palliative care in the pediatric setting, and to our knowledge, only two tertiary centers offer a specialized PPC service. Besides the University Children's Hospital of Zurich, the University Children's Hospital of the Canton Vaud has developed a PPC program [7]. To initiate a service for PPC, it appears important to evaluate needs and expectations for such a service from the perspectives of users, affected families, and health care professionals (HCPs) and to also address possible barriers. The main goals of this study were to (1) describe the needs of pediatric HCPs taking care of children with palliative care needs and (2) develop a concept for the first Center of Competence for PPC in Switzerland.

Methods

This study consists of two parts: Part 1 was part of a larger project that included interviews with HCPs as well as with 15 parents whose child was receiving palliative care or was recently deceased [10]. Part 2 was developed on the basis of part 1, to obtain a more detailed view of the needs of HCPs involved in the care of children with life-limiting diseases. To explore the broad spectrum of heterogeneous perceptions of HCPs including unexpected aspects and to gain in-depth insight into individual needs and expectations, a qualitative study method with semi-structured interviews was chosen.

In part 1, we recruited 21 HCPs from four children's hospitals (Aarau, Lucerne, St. Gallen, and Zurich) in different regions of the German-speaking part of Switzerland. The selection of participants was criterion based and purposive, covering the most frequent life-limiting diseases (cancer, neurological disorders, and non-cancer/non-neurological conditions). Neonatology was excluded. From these hospitals, all HCPs contacted agreed to participate (12 physicians, 5 nurses, and a psychologist, social worker, physiotherapist, pastor, and teacher). To cover aspects of home care as well, two of the nurses were pediatric outpatient nurses (belonging to the Swiss umbrella organization "Kinderspitex"). All participants had long professional experience but were not specialized in PPC. Face-to-face interviews were carried out in the participants' work environment from September 1, 2007 through January 31, 2008. The local ethics committees approved the study procedures.

In part 2, we conducted interviews with 55 HCPs from the University Children's Hospital ($n=12$) and the Canton of Zurich ($n=43$) from February 4, 2009 through August 4, 2009. Of 57 invited professionals, 55 agreed to participate. The sample consisted of experienced and skilled professionals (48/55 with >10 years of professional experience) and included 18 physicians (without PPC specialization), 19 nurses (some specialized in PPC), as well as 18 therapists and nonmedical carers (social worker, psychologist, pastor, teacher, and physiotherapist).

Interview structure and data analysis

The interview guide (Table 1) was designed on the basis of international studies and reviews [4, 9, 16, 17, 20, 28, 29, 31] and slightly modified for the additional interviews in part 2. The questionnaire was pilot tested with three professionals and revised according to feedback. The second author conducted and transcribed the interviews for part 1; the first, third, fourth, and fifth authors conducted the interviews for part 2, and the third author analyzed these before presenting them to the whole group for further analysis, categorization, and ranking. The process of data analysis, using content analysis [18], has been described in more detail in the first publication [10].

Results

Results are presented according to overarching themes which emerged from the analysis of the interviews. Table 2 summarizes results with respect to specialties (e.g., oncology, neurology, and other specialties).

Definition of "palliative"

The participants in both parts defined palliative similarly to the way it is defined by the World Health Organization [37] and the ACT [1] and included aspects referring to the professionals' specialization. Thus, oncologists and professionals attached to oncology uniquely referred to patients with relapses of their primary cancer but also included patients with high-risk tumors or refractory disease in whom curative and palliative treatment elements may be applied concurrently. Neurologists described patients with severe progressive conditions who were no longer able to compensate for a deteriorating impairment, who needed increasing support, or in whom complications occurred more frequently (e.g., recurrent pneumonia). They also added children with high and complex care needs even if their condition was fairly stable. Specialists caring for children with cardiac or metabolic diseases or specialists from a pediatric intensive care unit (PICU) focused on the goal of treatment and characterized palliative patients as those without a realistic hope of cure or improvement. Nurses pointed out that the child's autonomy irrespective of age received more weight in a palliative situation.

"I think that palliative care means to live life most consciously until the terminal breath. We should focus on the needs of the child." (teacher, hospital school)

Some professionals from PICUs had the impression that the term palliative was misunderstood as an abandonment of hope or a sign of capitulation.

Table 1 Interview guide

Main topic	Interview question
Definition of palliative care	What does palliative care mean to you? When do you start palliative care in a patient?
Communication and information	How do you communicate a palliative situation to the family? How do you announce such a discussion?
Decision-making	What does the process of decision-making look like and who is involved? When and how are parents and patients involved?
Organizational aspects of care	How do you organize the care of an affected child and his or her family in the hospital or at home?
Place of care	Where does the palliative care of children from your specialty take place? How flexibly can you and your team react to changes of place? How is the care coordinated? How can you ensure continuity of care in the hospital and at home?
Provision of respite	How can you provide respite?
Place of death	Where do the children from your specialty die most frequently? With respect to the place of death, what are the most important influencing factors?
Bereavement care ^a	Do you provide bereavement care? If so, do you use an individual approach or do you have a uniform concept? What does this concept look like?
Needs of professionals	What do you need to feel better prepared in the care of these children and their families (e.g., education, training, and support by specialized palliative care teams)? Following the death of a child, how does your team take care of itself?
General judgment of palliative care	What do you think in general about pediatric palliative care? How important is palliative care in your specialty?

All questions were supplemented by the question of strengths and shortcomings within the particular issue and followed by a question about needs for improvement

^a Topic discussed only in part 2 with professionals from the University Children's Hospital of Zurich and additional professionals from the Canton of Zurich

Attitude toward PPC

It was appreciated that PPC was among the responsibilities of everyone working in pediatrics, and at the same time, it was emphasized that there was room for improvement. Many staff members felt that there were a multitude of myths around this part of life as well as barriers to talking about the limits of medicine and about dying.

“Palliative care becomes an issue in my specialty as these patients live longer. The limits of what cardiology can offer are now moving toward adolescence and young adulthood.—There is a gap of knowledge and skills concerning how to deal with these young people.” (cardiologist)

“For the kids this (PPC) is nearly the most important part of care. We are not allowed to escape. Unfortunately, there is a tendency to do so.” (specialist in metabolic diseases)

“Palliative care is still a taboo in our society and there are many myths around it. We need to talk more about

palliative care issues as these belong to our life and also to our profession.” (general pediatrician)

Current provision of PPC

Composition of teams and mode of practice

All participants reported high flexibility and willingness in the care of these children and families. Flexibility was also highlighted with respect to place of care and patients' needs and wishes. However, two shortcomings were particularly reported: lack of structures to staff the child's care in hospital or at home and lack of human resources to realize individual care during busy shifts or complex situations. Some interviewees were in favor of the pediatric oncology structures, where, for example, weekly interdisciplinary conferences take place to exchange information on currently hospitalized patients and patients at home. To insure information flow, a representative of Kinderspitex is also present. Some professionals from the hospital, particularly physicians, were also involved in the care at home by visiting the child and its family or by meeting the family doctor and

Table 2 Composition and mode of practice of existing teams

Specialty	Current situation	Professionals' evaluation		Needs and wishes for the future
		Positive aspects	Negative aspects	
Oncology	Hospital care			
	Regular ^a : doctors, nurses, psychologists, social worker, nursery school teacher/teacher, and physiotherapist	High commitment and flexibility of all professionals involved in the care of an affected child/family	Team size often too large	Team members with PPC training
	Optional ^b : pastor			More flexibility and resources to support home care
	Home care			
	Kinderspitex, family doctor (GP, pediatrician), and hospital's oncologist	Well-organized Kinderspitex	Lack of training in symptom management Lack of information about the child's needs (Kinderspitex)	PPC team available for support
Neurology	Hospital care			
	Regular: doctor, nurse	Patients are mostly at home	Lack of PPC knowledge (doctors)	PPC team available for support
	Home care			
	Kinderspitex, pediatrician, and physiotherapist	Collaboration with Kinderspitex	Lack of neuro-pediatric and PPC knowledge	Improvement of collaboration between specialists and family doctors
Other specialties (metabolic diseases, cardiology)	Hospital care			
	Regular: doctor, nurse	In general good contact with families	Lack of structure to coordinate care	Psychologist and social worker as regular team members
	Optional: pastor, nursery school teacher/teacher, and physiotherapist	Nurses play an important part	Lack of continuity and availability of professionals	Regular meetings with other "players" (e.g., ER and PICU) to improve exchange of information
				For families affected by very rare diseases: a place to meet other families
	Home care			
	Kinderspitex, pediatrician	Good collaboration with Kinderspitex	Lack of structures that ensure coordination and continuity of care	Continuity between hospital and home care Collaboration with long-term institutions

Kinderspitex outpatient nurses, GP general practitioner, ER emergency room

^a Regular means the most common composition of the team

^b Optional includes additional HCPs in the attending team

the Kinderspitex nurse to discuss treatment or to provide emotional support. Many of these activities happened outside of working hours.

"My dream would be that we were more involved in the care at home. We would visit the patient and family and support the team at home and thus realize 'continuity of care'." (nurse, oncology)

"It would be helpful to have some kind of a 'pool' which could always allocate an extra nurse to take over duties; thereby one nurse could stay with the dying child and his or her family." (nurse, oncology)

"For children from neuro-pediatrics, it would be helpful to have round-table discussions like in oncology or to receive the discharge letter for at least some information about the child." (nurse, Kinderspitex)

In principle, both hospital and Kinderspitex nurses noted that the success of care very much depended on the persons involved, especially physicians. There was substantial agreement among all professionals that support from a PPC team could improve the current situation, particularly with respect to the coordination of care but also symptom control. In terms of mode of practice, several professionals

outlined areas that needed attention: first, the question of when to start palliative care; second, decision-making and communication with families; third, standardization of the palliative care setting; fourth, symptom control (particularly pain, dyspnea, fear, and agitation); and fifth, transition to adult palliative care.

Communication with parents and the child

Many HCPs reported their unease in talking about dying and death with parents and using the word “dying”. In contrast, oncologists reported already using “life-threatening” when the diagnosis of cancer is made. However, in the case of a high probability of death within weeks, physicians did not want to lose time and communicated more directly. In neurology, the life-limiting character of an illness would also be announced at the time of diagnosis, and “death” as one scenario might be mentioned as early as that. One cardiologist self-reflects:

“Some parents appreciate what the illness is about when clear words are used [...]; following those conversations, care often becomes much easier.”

One physician of a PICU emphasized the setting of this kind of conversation with parents:

“It is crucial—and I did not realize this when I was a young doctor, but today I recognize it when observing colleagues, that they do not choose the best possible setting—parents need a quiet atmosphere without being interrupted repeatedly. Then they may express their sadness and fears, and may also be able to cry.”

The process of decision-making

A number of participants reported well-planned and interdisciplinary settings (including ethics rounds), when difficult treatment decisions had to be made, such as changing goals of treatment, withholding, or withdrawing therapy. The conversation with parents would then take place in a more intimate setting, including the doctor and nurse responsible, and sometimes the psychologist, all having the family's trust. Parents were allowed to decide on additional participants (e.g., close friends or a family doctor). The involvement of the child was left up to the parents. Involving the child was deemed important by nearly all professionals, particularly in older children (>10 years) or if death was expected to occur soon. For the most part, nurses felt integrated in the process of decision-making. They often played a central role in bridging or channeling the communication with the attending specialist and in supporting families who frequently addressed their additional questions to a nurse or asked for her opinion.

“Parents want to discuss treatment options and ask what we think about it. We need to be extremely

careful in what we answer. But it is important to demonstrate our willingness to listen and to figure out what could be helpful to alleviate their process of decision-making.” (nurse, oncology)

Irrespective of specialization, many physicians would appreciate guidelines on how to prepare parents who are going to lose their child. Neurologists expressed needs for advanced care planning and some sort of advanced directives that could prevent children from unnecessary procedures or treatments in the case of unplanned admissions. Nurses in particular expressed the need to better document important conversations with the family, which would also allow parents to review aspects of information. In addition to these documents, brochures on palliative care or the process of dying could be handed over to the families.

Provision of respite care

In Switzerland, families provide a large portion of their child's care when it is suffering from a complex chronic disease and receive support from Kinderspitex. Short-term respite care for families burdened with the care of their child is either provided by Kinderspitex or by the hospitals where children may be placed for short periods. Occasionally, Kinderspitex staff accompanies families on vacations. In the view of many professionals, respite care for these families is an unsolved issue in Switzerland. However, the idea of a hospice was not seen as a fully satisfying solution. Three main reasons were given: (1) parents would not want to be outside of their home; (2) families would prefer more intensive support in their home; and (3) mothers would feel even more isolated than at home. On the other hand, particularly physicians and professionals from psychosocial services reported difficulty in finding financing for such costly care at home or to find a place for a child with complex needs to unburden a family or allow some time with healthy siblings. In this context, some physicians and other professionals valued a hospice as a good place for the provision of respite care. In addition, one physician envisioned a hospice as a safe place for families to share the fate of a beloved child with a life-limiting disease. Another physician suggested:

“As it already exists for adults, a hospice could provide help with the care at home—stay with a child overnight to allow parents some rest.” (PICU physician)

Thus, this issue remained somehow open and inconclusive.

Place of death

The place of death appeared to be strongly associated with the diagnosis of the child. Neurologists thought the hospital was the “better” place of care for children with severe

muscular disorders or unexpected acute deterioration in complex chronic conditions. In addition, the experience of a team regarding palliative and end-of-life care seemed to influence the place of death. Teams with extensive experience tried hard to enable a family to care for their dying child at home. Besides giving security and confidence, dying at home was accomplished through continuous phone support, short visits at home, or even by accompanying the family when going home. On the other hand, it was argued that some parents felt lonely with their dying child at their home.

Bereavement care

Several specialties and wards (particularly PICUs) invite parents to talk about the last days of life and to receive information about the results of a post-mortem examination. However, no structured bereavement care has been established so far. Although some professionals wrote condolence cards, attended the funeral, or visited the family, these signs of sympathy depended on one's own initiative and occurred merely occasionally.

Within the team, many professionals appreciated the culture of coming together after the death of a child and sharing experiences about the deceased child or talking about the terminal phase. Thus, team members had the opportunity for debriefing and bringing to a close their personal experience and relationship with the child and its family.

The needs of professionals

Particular needs of professionals

Physicians emphasized their need for support and supervision, particularly to improve communication with parents. They reported that they had never been taught how to do it and seldom received any feedback from parents or colleagues. Guidelines on how to structure these difficult conversations were thought to be helpful. Furthermore, it was emphasized that it would be important to develop a network which would facilitate contacting HCPs with specific knowledge on certain diseases or issues of care and gaining knowledge about the care of these unique children. Finally, the need for education in palliative care starting in medical school and continuing through postgraduate training was highlighted. Structure, knowledge, and skills should replace the motto “by instinct” or “learning by doing”.

The role of PPC teams and a Center of Competence of PPC

Three modes of support were predefined: (1) consulting and coaching, (2) teaching, and (3) written guidelines. In general, the need for a standardized concept of PPC was highlighted. For the provision of PPC, nearly all physicians and

a large proportion of nurses considered the support of a consulting PPC team important. This would predominantly include team coaching for difficult and complex patients with regard to decision-making, symptom management, and coordination of care. Guidelines and formal teaching were evaluated as being less important, particularly from those working in hospitals. However, to better define patients and families who might benefit from PPC, an assessment instrument providing objective criteria was deemed desirable. In addition, there was considerable agreement on the necessity of a standardized concept of bereavement care for all families affected by the death of a child. For team members, as well, there should be an opportunity to receive support following the death of a child.

Discussion

This study describes the current situation of PPC in the German-speaking part of Switzerland from the perspective of HCPs and formulates measures to improve and further develop PPC provision in Switzerland. In contrast to the frequently reported reluctance of HCPs, particularly physicians, to consider a palliative care approach in an individual patient [5, 30] or to involve existing specialized PPC teams [12, 21], the generally positive and open-minded attitude of our study participants toward PPC is remarkable. Besides the recognition and acceptance of boundaries of what medicine can offer and achieve, PPC emerged as a conceivable and distinct concept of care that offers a service and network across different settings and thus meets the needs of families affected by life-limiting illness. A similar encouraging finding has been reported in a survey among 293 German general pediatricians [13], demonstrating a high disposition to engage in palliative care and to involve specialist PPC consultation teams. Regarding practical implications for PPC in Switzerland, our results encompassed five areas of PPC: (1) when and how to initiate PPC; (2) the role and tasks of a specialized PPC team; (3) transition from pediatric to adult services; (4) respite care and the potential role of a hospice; and (5) bereavement care.

Despite a rather homogeneous definition of PPC, several difficulties were raised that may interfere with a timely initiation of PPC. These included an uncertainty about when to start palliative care, uncertain prognoses in many children, and—probably closely related—unease about communicating a “palliative situation” to parents or to use the word dying. The discomfort related to the term palliative and insufficient communication skills are well-known difficulties or even barriers to the provision of PPC [5, 6, 24, 30]. To overcome these, education in basic palliative care and communication skills in addition to PPC specialist support on site have been highlighted in previous studies [13, 28].

Another reason for discomfort in communication about dying and death could also be related to moral distress on the part of the HCPs themselves [3, 32]; however, to confirm the latter, a more detailed study approach would be needed.

The role and tasks of specialized PPC teams in Switzerland would primarily include support of hospital- and home-based teams in the care of a child and its family (e.g., coordination of care and symptom control) and to some degree the direct support and care of a child. This kind of support has been named “consultation service” and has been described as a reasonable and cost-effective model of care by several groups [19, 28, 33, 34]. With respect to pediatric subspecialties, the collaboration of specialized PPC teams and pediatric oncology, cardiology, neurology, metabolic diseases, and PICUs in tertiary centers and the ongoing involvement of the specialist, e.g., an oncologist or nephrologist, would ensure disease-specific support and continuity of care [22]. Continuity of care may also be achieved by the ongoing involvement of the specialist, e.g., an oncologist or nephrologist, to ensure disease-specific support.

Regarding a specialized PPC team in a Center of Competence for PPC, several expectations and wishes were formulated. These included: developing structures that allow a better coordination of care in hospital or at home; developing an instrument that would help to identify children with PPC needs; guidelines on aspects of how to prepare and accompany parents who are going to lose their child; some sort of advanced directives for children with life-limiting disease to prevent them from unnecessary procedures and treatments; and documents and information for parents that are accessible for them whenever they need it.

In the context of pediatric subspecialties, aspects of transition may need consideration. Hence, children with congenital heart diseases may successfully undergo surgical interventions and survive childhood; however, they remain at risk of premature death from progressive heart failure during early adulthood. This has been demonstrated in a recent publication of Tobler et al. [27] on 48 patients with congenital heart disease who died at a mean age of 37 ± 14 years. They described circumstances of death, end-of-life discussions, and the provision of end-of-life care and showed that only a minority of these patients had documented end-of-life discussions prior to their terminal admission and most of them received continuing aggressive medical treatment up to their demise.

In contrast to our first study, where we reported on parents' preference for home-based respite care [10] rather than respite care provided by designated hospice houses, a few respondents in the current study elaborated on the usefulness of a hospice as a place of respite care but also as a safe place for families to share their fate with others. Particularly physicians and professionals from psychosocial services mentioned the increasing difficulty of financing costly care at home.

The lack of bereavement care for families has been acknowledged in the literature [4, 35], and it has been shown that signs of sympathy have a positive impact on parents' long-term grief outcome [15]. Participants in our study reported some efforts towards bereavement care several during the terminal stage of a child and after the death of a child. However, improved structures that facilitate an appropriate and dignified farewell between the families and the professionals are urgently needed. Kreicbergs et al. [15] strongly recommended a closing session with the attending staff after the death of the child. With respect to long-term support or support in “complicated grief reactions”, a specialized PPC team, particularly psychologists, could be contacted for further grief counseling by parents and siblings. Others have reported that interventions or social events to reduce feelings of isolation in bereaved families are helpful [36].

There are several limitations to this study. First, the sample is small and heterogeneous and consisted of two study parts. The reason for this two-part approach was to obtain as many perspectives as possible in a short time. However, the results may not be generalizable for Switzerland. Second, part 2 of the study was performed by the same people who planned to develop the concept for the Center of Competence for PPC and thereby may have led to a bias in the way that respondents within the same institution formulated critical or negative aspects concerning the development of PPC. Future research, following the first steps of PPC implementation in Switzerland, should embrace a larger sample of HCPs and also evaluate differences between the German-, French-, and Italian-speaking parts of Switzerland.

Conclusion

The need for PPC as an overarching specialized service inside and outside of centers providing top quality medical care (Spitzenmedizin) has been widely acknowledged. PPC should offer a broad range of support for attending teams as well as for affected families, which particularly includes coaching of teams, coordination of care, symptom control, and bereavement care. Respite care has been recognized as an urgent need for families who are caring for children with long-lasting complex chronic conditions. Hospices may also be an option in Switzerland; however, there was a debate as to whether families would use them. Apart from that, a place to meet other families with similar destinies could be a valuable alternative.

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Conflict of interest The authors declare that they have no conflicting interests.

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